“ Disclosing High Risk Medical Conditions to Patients”

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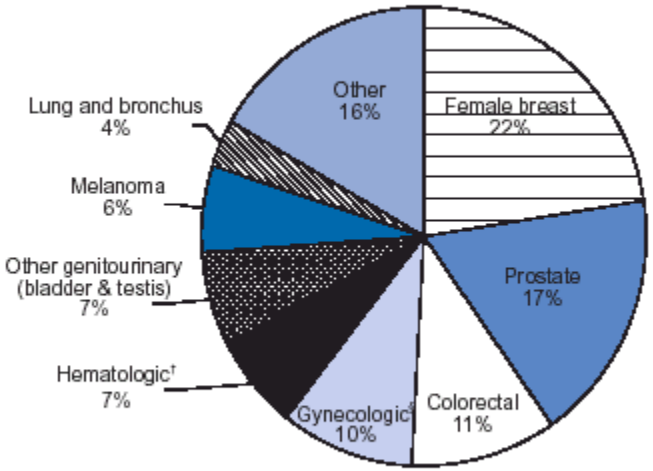
Medical Disclosure: What happened?

The son was a fixture in the room since last week, after his 84-year-old mother, Jean Davis, was brought there for surgery related to cancer treatment. While speaking to Dr. David B. Cohen around 11 a.m., the son pulled a semiautomatic handgun from his waistband.

CANCER DISTRIBUTION (2001)

FIGURE 3. Distribution of primary cancers* among living persons who have ever received a cancer diagnosis — United States, 2001



*Only first (primary) cancer site counted.
†Hodgkin's disease, non-Hodgkin's lymphoma, and leukemia.
§Cervix, corpus uteri, and ovarian.

The Disclosure and Medical Provider's Response

- " There is nothing else I can do"
- " Good Luck to you"
- "Got some really bad news for ya"
- " Stay here, I will be right back"
- " My secretary will call you with some a few appointments"
- " Hang in there"

The Disclosure and Patient's Response

- The Patient's Reaction:
  - Shock
  - Disbelief
  - Denial
  - Fear
  - Anxiety
  - Depression
  - Sense of uncertainty
  - Foreshortened Future
  - Despair

Breaking the Diagnosis

- What is Bad News?
  - Usually defined as "worst case scenario," actually, it can be any information that adversely and seriously affects an individual's view of his/her future.

Breaking the Diagnosis

- Why is it Hard to Do?
  - No training and little experience, especially with children and youth.
  - Messenger may feel responsible.
  - Reluctance to change doctor/patient relationship. Secondary v. Primary roles
  - Not knowing patient/family, background, resources, or spiritual beliefs.

Research Studies

- A study of 95 gynecological cancer patients, two years after diagnosis:
  - 57% reported they needed help in dealing with cancer related emotional issues
  - 35% received such help
  - 73% reported that the physician should ask if they need help dealing with emotional aspects of illness

(Miller and Pittman,2003)

Research Studies

- The largest group of cancer survivors had been diagnosed with Breast Cancer (Hewitt,2000). This group has a well defined psychosocial research database.
- More research is needed with ethnic minorities.
- The number of people living with a history of cancer continues to increase but methods for promoting the health and well-being of long-term survivors and individuals who encounter recurrent disease are needed.

Research Studies

- In a study of 273 cancer patients receiving palliative chemotherapy and 10 of their oncologists:
  - 94% of patients reported a desire to discuss their emotional functioning with the physician
  - 39% of patients indicated they would do so only if the physician initiated the discussion
  - 4 oncologists reported it was their task to discuss the emotional issues with the patient
  - 6 oncologists reported they would share the task with other health providers
  - None of the oncologists indicated they would have initiated the discussion

(Detmar, S.B.,2000)

Research Studies

- In a randomized trial with patients and oncologists, both were provided with a summary of the patient's standardized quality of life assessment before consultation. The patient received more counseling from the oncologists on how to manage problems.
- This did not result in an increase in referrals to other professionals or prescription for medications.
  - (Detmar,2002)

Depression

- Research shows the incidence of major depression in terminally ill patients ranges from 25%-77%.
- When addressing terminally ill patients consider:

  A. Prior History of Depression

  B. Prior suicide Attempts

  C. Social Stressors

  D. A history of substance abuse

  E. Family history of depression/family cancer outcomes

Research Studies

- 1. Moderate to Severe depressive symptoms improved at the six-month interval when the patient's cancer-related needs, quality of life, and depressive symptoms were presented to the Doctor and Nurse before the patient's consultation. (McLachlan,2001)
- 2. Psychosocial interventions more effective for individuals with less resources such as low interpersonal supports, less optimism, lower education. Individuals with more resources recovered in their natural environment. (Lepore, S.J.,2003)

Family Centered Cultural Competent Communication:

Breaking the Diagnosis

Breaking the Bad News

Breaking the Diagnosis

- Why is it Hard to Do? (continued)
  - Fear of patient/family's emotional reaction.
  - Not having answers to possible questions.
  - Discomfort with own emotional response.
  - Embarrassment at having promoted too optimistic of an outcome.

Breaking Bad News, 2003

Breaking the Diagnosis

- Who Should Deliver Bad News?
  - The patient's first choice is their Primary Care Physician (PCP).
  - PCP's often prefer to remain the "good guy" and leave breaking bad news to the specialist.
  - Physicians agree that it is easier to break bad news to families/patients that they know well, than to relative strangers.
  - If the PCP cannot deliver the news then a specialist who has an ongoing relationship, and will continue to do so, is the next best option (Travaline, J., 2002).

Breaking the Diagnosis

- Who Receives Bad News?
  - A physician's primary responsibility is to deliver the news to the patient and in the case of a child to the family.
  - Evidence shows that patients/families increasingly want information regarding diagnosis, chances of cure, side effects of treatment and realistic estimates of time left.
  - Lack of this type of information causes patients/families undue worry.

Breaking the Diagnosis to the Young

- Who Receives Bad News? (continued)
  - Follow through with Family-Centered Care and get to know the patient/family.
  - Consider the age, also developmental age, and personality of your patient.
  - If the patient is a teenager or young adult ask them who they want to have present.
  - Remember that a family's culture will affect their response to news and may determine who needs to be present during the discussion.

Tips (continued)

- Prepare Your Patient/Family
  - At Time of Breaking Bad News to Children/Families
    - Ask child/youth what they know about their illness.
    - Child may realize something is wrong and knowing what that is may be comforting in itself.
    - Be aware of how much information a child wants at any given time, and respect his/her wishes.
    - Respect the family's wishes regarding information.

Tips on Breaking a Difficult Diagnosis

- Prepare Yourself
  - Review patient's records, background, history, test results, future management/treatment options.
  - Mentally rehearse, anticipating questions, emotional responses.
  - Ask a colleague, patient's nurse to accompany you.

Tips (continued)

- Prepare the Setting
  - Arrange privacy, a non medical room is best.
  - Allow the patient to get dressed, especially if they are pre-teen or older.
  - Sit down near the patient, be sure to provide enough seating for all in attendance.
  - No pager, phone interruptions.

Tips (continued)

- Prepare Your Patient/Family
  - At time of tests (when condition is suspected), ask patient/family how they prefer to be informed of findings: "Are you a person who likes all the details or would you prefer an overview?"

Tips (continued)

- At Time of Breaking Bad News
  - Warn them the news are coming, “I am sorry to have to give you some bad news,”
  - Use language the patient can understand, use non-technical words, avoid bluntness, and give accurate information.
  - Give the information in small chunks, stop to check for understanding. “Would you like me to explain more?”
  - Support verbal information with written information

Breaking Bad News, 2003)

Tips (continued)

- At Time of Breaking Bad News (continued)
  - Make yourself available to answer questions, have another meeting as needed, especially during the first 24-48 hours.
  - In a 1994 study of 358 cancer patients, 75% of families felt that a failure of receiving adequate information about the illness created undue worry (Girgis, A. and Sanson-Fisher, R., 1998).
  - Don't say "there is nothing more we can do for you," goals of care change to pain control and symptom relief.

Tips (continued)

- Provide Support
  - Acknowledge and identify with the emotion experienced by the patient/family.
  - If there is silence, use open-ended questions “What are you thinking/feeling?”
  - Avoid saying “I know how you feel,” even if you have similar personal experience; try an alternative such as, “I can only imagine what you may be feeling.”
  - No one really knows how another is feeling.

Tips (continued)

- Provide Support (continued)
  - Allow patient/family time to express emotions, let them know you understand and acknowledge their feelings.
  - Unless patient/family emotions are adequately addressed it may be difficult for doctor and patient to move forward to other important issues (Breaking Bad New, 2003).
  - Remember: This is the patient's crisis not yours – listen!!!

(Travaline, J., 2002)

Tips (continued)

- Provide a Plan
  - Provide a clear plan for the future.
  - Discuss treatment options or management plan (Breaking Bad News, 2003).

Tips (continued)

- Document
  - Record who was present, what was said (specific words used in describing condition), patient/family response and options discussed.
  - Immediately provide copies to entire healthcare team, especially PCP, if not present.

Tips (continued)

- Debrief
  - Breaking bad news is difficult and emotional for both patient/family and the healthcare provider.
  - Providers who take time to debrief with a colleague experience less anxiety and are better prepared for their next patient.

Screening Instruments

1. Depression is a significant symptom for many palliative care patients.
2. Many tools, however, have been developed for physically well patients and it is important that tools are validated for the populations in which they are used.
3. 'Are you depressed?' was the tool with the highest sensitivity and specificity and positive predictive value.

   (Palliative Medicine,2003)

SCREENING INSTRUMENTS

Are one or two simple questions sufficient to detect depression in cancer and palliative care? A Bayesian meta-analysis

Seventeen analyses were found. Of these, 13 were conducted in late stage palliative settings

A single ‘depression' question enabled the detection of depression in 160 out of 223 true cases. The two-question combination facilitated a diagnosis of depression in 138 of 151 true cases . (Mitchell,AJ,2008)

Screening Instruments

- Two hundred and nine consecutive patients were assessed for ADs and MD using a structured clinical interview at the time of their registration with a palliative care unit, and two single-item interviews (‘‘Are you depressed?’’ and ‘‘Have you lost interest?’’)and the Hospital Anxiety and Depression Scale (HADS) were administered. Screening. AD
- J Pain Symptom Manage 2006;31:5--12

Research Studies

- 1.Interventions designed to enhance capacities to monitor and alter cancer-related thoughts, emotions, and behavior produce better results(e.g., practice of new coping skills, relaxation training, role playing, goal setting, problem solving). (Graves,2003)
- 2. Psychoeducational interventions are better than peer discussion(Rehse, B.,2003)
- 3. Educational interventions more successful at maintaining quality of life indicators of vitality, bodily pain, and physical functioning(Helgeson V.S.,1999)

BEYOND SCREENING TO TREATMENT

- 1.ASSESSMENT OF PSYCHOLOGICAL SYMPTOMS
- 2. ASSESSMENT OF SUICIDE RISK
- 3.EVALUATION FOR TREATMENT
- A. PSYCHOTHERAPY (INDIVIDUAL, FAMILY)
- B. MEDICATIONS AND POSSIBLE PHYSICAL INTERACTIONS

Hope and Pain Relief should be the core focus when alternatives are limited.

Works Cited

- The following references were retrieved February, 2004 from http://www.findarticles.com.

- American Academy of Pediatrics, Committee on Early Childhood, Adoption,
  And Dependent Care, 2000-2001. The Pediatrician's Role in Family Support Programs (Electronic Version). *Pediatrics*, January, 2001.
- American Academy of Pediatrics, Committee on Hospital Care, 2002-2003.
  Family-centered care and the pediatrician's role. (Policy statement: organizational principles to guide and define the child health care system and/or improve the health of all children). *Pediatrics*, September, 2003.
- *Breaking Bad News. . . Regional Guidelines. Developed from Partnerships in Caring (2000)*. Castle Buildings, Belfast, Ireland: Department of Health, Social Services and Public Safety. February, 2003.
- Girgis, Afaf and Sanson-Fisher, Rob W. Breaking Bad News 1: current best advice for clinicians. *Behavioral Medicine*, Summer, 1998

References

1. Breaking Bad News: Regional Guidelines. Developed from Partnerships in Caring(2000). Castle Building, Belfast, Ireland; Department of Health, Social Services and Public Safety. February,2003.
2. Breaking Bad News: Girgis and others, Current

   Best Advice for Clinicians. *Behavioral Medicine, Summer,*1998.

The End